

OCTOBER 30, 2013 MINUTES
DATA SECURITY AND PRIVACY COMMITTEE
ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY

The Illinois Health Information Exchange Authority (“Authority”), pursuant to notice duly given, held a meeting of the Data Security and Privacy Committee on October 30, 2013 at the Bilandic Building in Chicago, Illinois, with telephone conference call capability.

Committee Members Present:

Dr. Nicholas Panomitros, Chair
Elissa Bassler
David Carvalho
Jud DeLoss
Debbie Hayes (phone)
David Holland (phone)
Pat Merryweather (phone)
Mick Skott
William Spence (phone)

Committee Members Absent:

Jay Anderson
Jennifer Creasey
Dr. Carl Gunter
Harry Rhodes
Tiefu Shen

Welcome and Attendance

Dr. Nicholas Panomitros, Chair, announced changes to the Committee’s membership: 3 new members were added including, Mick Skott of Lurie’s Children Hospital, Debbie Hayes of Blue Cross/Blue Shield of Illinois, and Jay Anderson of Northwestern Memorial HealthCare. It was announced that Leah Bartelt of the ACLU of Illinois has stepped down.

In accordance with the Open Meetings Act, the Authority posted notice and an agenda of the meeting physically and on the Authority website more than 48 hours in advance of the meeting.

Dr. Panomitros thanked the Work Group chairs, including Marcia Matthias, Dave Carvalho, Laurel Fleming, David Miller, Peter Eckhart and Harry Rhodes.

Brief Explanation of Preliminary Issues (PowerPoint Presentation)

In describing the purpose for the meeting of the Committee, staff reviewed that the

Authority Board adopted the 2013 Committee report, which found in part that the Mental Health and Developmental Disabilities Confidentiality Act (MHDDCA) presented a barrier to the full-functionality of the ILHIE. OHIT and Authority thereafter worked to pass House Bill 1017 to amend the MMDDCA. Both chambers of the General Assembly adopted the Bill unanimously. In the bill, the Authority was delegated responsibility of the implementation of patient-opt out, data segmentation, and data review. Work Groups were convened to implement the Bill and generated recommendations that are before the Committee today. The recommendations are in the form of draft Attachments A – H. (ILHIE Notice, Attachment A; ILHIE Signage, Attachment B; ILHIE Website Content; Attachment C; Opt-Out Form, Attachment D; Opt-In Form, Attachment E; Authority Patient Opt-Out Choice and Meaningful Disclosure Policy and Procedure, Attachment F; Break the Glass Recommendation, Attachment G; and Breach Response Policy, Attachment H).

Three Work Groups were created in June 2013: Patient Choice and Meaningful Disclosure, Breach Response, and Patient Consent Preferences and Data Security. A timeline was created and stakeholders were invited to participate to offer different perspectives in open meetings. Each Work Group had an action plan and deliverables. The Patient Choice and Meaningful Disclosure Work Group created meaningful disclosure resources, the Breach Response Work Group created standards for breaches, and the Patient Consent Preferences Work Group is evaluating data segmentation technology and patient privacy and security concerns on an ongoing basis.

Overview of the ILHIE

The ILHIE is an opt-out exchange and the standard Authority policy is to set each patient's preference as opted-in. However, if a patient has specially protected health information with a particular provider, the patient will be opted-out by default. These patients will only be able to opt-in at the provider's office to be sure they receive meaningful disclosure and give consent that is required before the data is shared. The Work Group recommends to the Committee that meaningful disclosure under HB1017 requires a written Notice about what the ILHIE is and the risk and benefits of participation, and provider ILHIE Signage to continually alert patients that the provider is an ILHIE participant.

Each provider is responsible for providing meaningful disclosure. Therefore, a provider can provide the ILHIE notice more frequently than just one time. A provider might want to give notice if a patient comes into specially protected information. A patient can submit Opt-Out Form in one of two ways: 1) the patient comes into the provider office and fills out the form or 2) the patient takes the form home or pulls it from the website and then the patient get the form notarized (to ensure that it is legitimate) and sends it in.

Public Comments

The ACLU, the AIDS Legal Council of Chicago, and Equip for Equality prepared public comments.

Colleen Connell, ACLU-IL Executive Director:

The ACLU remains concerned that policy circulated on Thursday does not add assurances to each patient the opportunity to make meaningful choices. To ensure this, patient notice materials must be more specific and drafted in simpler terms and offered more frequently so that patients appreciate the need to assess and reassess their status, especially in light of altered circumstances.

The ACLU is concerned about patient confusion. The patients are not told to opt-out or all of their information will be accessible through EHR Connect. EHR Connect cannot exclude specific information from being shared. "All-in or all-out" should be stated upfront and directly. If there is anything the patient does not want to share, the patient should consider opting out because EHR Connect cannot exclude specific information from being shared.

More information should also be shared about specially protected health information. The more explicit statement, that a patient is all in or all out, is too little and too late in the document. Patients would benefit from an earlier and more explicit statement in the notice. Also it should be made clear that if a patient gives consent, that information may be shared with all providers and insurers, if any are on the ILHIE, even if a patient does not want a specific physician to have access.

The ACLU indicated that the Working Group discussed the need to have the patient notice in terms that are understandable for a 5th grade reading level. The documents opt-out/opt-in are not digestible for a 5th grader.

The ACLU is also concerned each patient will be offered the ILHIE notice during the first patient encounter, which is not frequent enough. The one-time offering does not reflect the multitude of changed circumstances. For instance, if the patient has a genetic test, the patient may have new concerns about risk of discrimination and stigma and may not recall that he had not opted out before. A single notice will not ensure that patients understand the implications of sharing new information. Patients with specially protected information should get notice more frequently. Also, the only acceptable reason not to give notice at the first encounter would be a medical emergency.

ACLU supported the proposed patient opt-out choice policy that requires minors, at age 12 and older, to exercise participation decisions. The ACLU is of the view of a dual consent as a parent or guardian would be inconsistent with self-consent under IL law to many services (pregnancy test, HIV, substance abuse). A dual consent might deter a minor from getting care or treatment.

The ACLU indicated it would be happy to submit a nominee for membership on the Committee.

Question to ACLU: With regards to the frequency and timing of notice, what did you

have in mind?

Response: It is important to understand the Work Group's recommendation is that a "provider" is the entity that contracts with the Authority. Under the recommendation, the patient receives the ILHIE Notice the first time the patient encounters the provider once they become an ILHIE participant. The ACLU does not think patient needs notice every time they get care, but that a patient needs clear notice for care that would create specially protected health information. Other patients should also get notice annually.

Question to ACLU: Would it be reasonable to keep giving notice? The more complicated it is for providers, the more difficult it is for providers to comply. People will fall through the cracks. Can the ILHIE send an annual notice (like I get from the credit card company)?

Response: The ACLU remains convinced of the need for an additional level of notice when patient's come into specially protected health information. Two things are critical if the Authority ILHIE sends information: 1) Notice has to be really clear (at a 5th grade level) and 2) there has to be an opportunity for patients to ask questions. Also, since the MPI does not contain email addresses, sending a notice by email is not practical.

Question to ACLU: You have stated the public policy issue regarding 12 year old consent. We want to encourage people over 12 to get care and to do that, we encourage care that does not require the consent of parents. But is there legal authority for minors to determine if they can participate in the ILHIE?

ACLU response: The General Assembly gave the Authority the ability to pass rules and standards and to enter into contractual obligations that would govern how the ILHIE would be implemented.

Ruth Edwards, AIDS Legal Council of Chicago:

It is important that HIV patients get meaningful disclosure about who will have access to patient information through the ILHIE. It must be made clear that insurance plans and self-insured employers may have access to this information. Disclosure must be clear that all the information may be shared with all current and future providers. AIDS Legal Council recommends making a separate notice about specially protected health information for people who test positive, so they can reconsider their choice to opt-out. Patients should get regular opportunity to reconsider their consent as special circumstances emerge.

Question to AIDS Legal Council: What is the HIV age of consent?

Response: People 12 years old and up can consent to testing and treatment and counseling without a parent's knowledge.

Question to AIDS Legal Council: If not just once, how frequently would you want

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meaningful disclosure?

Response: It is particularly crucial to get notice around testing. It could be confusing if someone has already participated in the ILHIE and then consented to an HIV test.

Cheryl Jansen, Equip for Equality (submitted written comments)

There were no additional public comments.

ILHIE Authority Website Information

Danny Koppelson of OHIT discussed the recommended Authority website content. He reported that the Work Group looked at information from different states in deciding what would be put on the website.

Mr. Koppelson walked through the proposed website content. The goal was a simple FAQ format that is promotional and shows the benefits of EHR Connect.

Clarifications to the question on page two asking “Will HIV and assault records be shared?” were discussed and made. The response was revised to read: "yes, unless you opt-out".

Comment: The Committee should take into account that the providers understand their confidentiality requirements. Psychotherapy notes need an authorization. There is an obligation among health care providers not have that information subject to query.

Response: It must be recognized that providers have obligations under the law and built in under the proposed ILHIE model. Each provider remains liable for their own legal compliance. The Authority cannot manage a provider’s consent process.

Dr. Panomitros recessed the Committee until October 31, 2013 at 1 pm.

[Note: Additional clarifying edits were made after Committee approval of the minutes].